

1993

The Effects of normalized occupation on the lives of adults with mental retardation

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DOI: <https://doi.org/10.31979/etd.85u3-6yjr>
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**The effects of normalized occupation on the lives of adults with
mental retardation**

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San Jose State University, 1993

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THE EFFECTS OF NORMALIZED OCCUPATION
ON THE LIVES OF ADULTS
WITH MENTAL RETARDATION

A THESIS

Presented to

The Faculty of the Department of Occupational Therapy
San Jose State University


In Partial Fulfillment
of the Requirements for the Degree
Master of Science

By

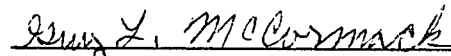
Jill L. Chesley

May, 1993

APPROVED FOR THE DEPARTMENT OF
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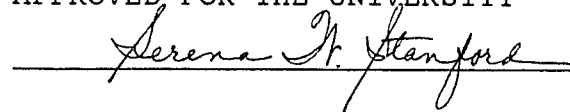


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ABSTRACT

THE EFFECTS OF NORMALIZED OCCUPATION ON THE LIVES OF ADULTS WITH MENTAL RETARDATION

by Jill L. Chesley

This study examined the effects of normalized employment on the leisure and self-care of adults, who are mentally retarded. The research was guided by the occupational performance frame of reference.

Case studies of five subjects and a significant other person for each subject are presented. Interviews yielded information about pre and post competitive work lifestyles. In addition, subjects were observed while working, during leisure pursuits and while engaging in self-care tasks.

Results of the interviews and observations were analyzed. The research identified shared experiences and variables which appeared to have influenced the non-work lives of people with mental retardation. The strongest effect of competitive employment was increased earning power which affected self-care, leisure, and socialization.

Acknowledgements

The author wishes to acknowledge her committee members for their guidance: Lela A. Llorens, Ph.D., OTR, FAOTA; Guy McCormack, M.S., OTR; and David Hoshiwara, M.S., OTR.

The subjects and their significant other people whose participation made this study a success are also acknowledged.

Special thanks are extended to my family and significant others for their love and never-ending support. Without their enthusiasm and confidence, this endeavor may not have been completed.

This thesis is dedicated to Terry Zimmerman.

Table of Contents

	Page
Abstract	iii
Acknowledgements	iv
Chapter	
1. Introduction	1
Purpose	1
Statement of the Problem	1
Objective	3
Questions	3
Definitions	3
Assumptions	6
Limitations	7
Significance of the Study	8
2. Review of the Literature	9
Mental Retardation	9
History of the Work Movement	12
The Value of Work	14
Frame of Reference	19
3. Design and Methodology	22
Purpose	22
Design	22
Questions	23

	Page
Subjects	23
Methodology	25
Procedures	25
Data Analysis	26
4. Data and Results	28
First Case Study "Lea"	28
Second Case Study "Larry"	37
Third Case Study "Mike"	46
Fourth Case Study "Roger"	55
Fifth Case Study "Lisa"	65
Results	75
5. Summary, Conclusions and Recommendations	77
Discussion of Results	77
Summary	87
Conclusions	89
Recommendations	90
References	92
Appendices	
A. Subjects' Informed Consent	95
B. Interview Form for Subjects	97
C. Observation Form	99
D. Significant Others Informed Consent	101
E. Significant Others Interview Form	103

CHAPTER 1

INTRODUCTION

Purpose

The first purpose of this study was to explore if there are observable and self-perceived associations between the acquisition of competitive employment and quality of life for adults who are mentally retarded.

The second purpose of this study was to attempt to describe skills and work behaviors of subjects. Skills include any capability a subject must have had to complete a specific competitive job, and the ability to maintain and increase competitive skills. Work behaviors include time management on the job, the ability to establish and maintain interpersonal working relationships with co-workers and supervisors, and the ability to initiate, concentrate on and complete a task.

Statement of the Problem

Individuals with developmental disabilities are able to work in competitive employment situations. Once a person secures a job, the potential to live independently exists as the person is able to support him/herself. Having a "real" job in Western culture is a sign of normalcy and normalcy is the status that many individuals with developmental

disabilities seek to achieve. As people gain independence in their daily lives, they are able to become contributing members of society, and thus feel more highly valued.

Securing and keeping a competitive job is often the first outward sign to society that a person who is developmentally disabled has overcome the retarded label. That person has tackled and learned skills in areas such as community mobility, social skills, work skills, personal care, and has developed a self-identity. He or she will have overcome tremendous odds against a sometimes non-supportive system of sheltered work, day treatment programs, board and care homes, and a society at large that sustains developmental centers and offers oppressive services for the "protection" of individuals with mental retardation.

The occupational therapy literature has not addressed the changes in lifestyle or quality of life of an adult with developmental disability who has become competitively employed. Nor has the literature identified acquired coping strategies "as perceived" by competitively employed adults with mental retardation, which may have been used to enhance their non-work lives.

Finally, no literature was found to address the variables (skills) that are most instrumental in affecting work and non-work roles.

Objective

The objective of this study was to describe the normalized work and non-work experience of a sample of adults with mental retardation who are currently working in competitive employment settings; focusing on their perceptions of how competitive employment may or may not have affected their lives. The research attempted to identify factors associated with their quality of life and adaptation to a more normalized lifestyle.

Questions

This study was designed to answer the following questions:

1. What are the differences perceived by persons who have mental retardation in their ability to be successful in non-work activities before and after engaging in competitive employment?
2. Which work behaviors learned at competitive jobs do individual adults with mental retardation and their significant others report as having an effect in their non-work lives?

Definitions

The following terms are used in this research and need to be defined:

1. Activities of daily living. (Also called ADL in this thesis) Those activities performed each day which are necessary for human function. Activities include bathing, grooming, dressing, meal preparation and maintenance of one's living space.

2. Adult. Any person over 21 years of age.

3. Competitive employment. Being employed in mainstream society where wages are comparable and the position of duties and expectations are like those expected of non-disabled individual doing the same job. Subjects participating in this research will be competitively employed. For the purposes of this study the term "normalized occupation" will be used interchangeably with competitive employment.

4. Developmental disability. A general term referring to any disability occurring before, during or after birth, which halts or disrupts development in persons under 18 years of age. The disability alters a person's development throughout life so that chances to learn and rate of learning may be different than "normal." For the purposes of this study, developmental disability refers to mental retardation.

5. Leisure time. Time spent in non-work, non-self care activities, in pursuit of vocational activities such as hobbies or community outings.

6. Mental retardation. "Significantly subaverage general intellectual functioning....resulting in, or associated with deficits or impairments in adaptive behavior.... with the onset before the age of 18" (American Psychological Association, 1980).

7. Non-work activities. Those activities performed when subjects in this study are not working at their competitive jobs. Also defined as leisure and self-care activities.

8. Non-work lives. A general term meaning all parts of the subjects' lives when they are not involved in competitive or volunteer work.

9. Normalization. "The utilization of culturally valued means in order to establish and/or maintain behaviors, experiences and characteristics that are culturally normative or valued" (Wolfensberger, 1977).

10. Quality of life. "The experienced degree of satisfaction of human needs.... a subjective measurement, a person's own appreciation of his/her life situation. This will usually depend on his/her physical well-beings, psychological situation, living conditions, relations and opportunities for meaningful activities" (Ahlsio, Button, Murray & Theorell, 1984).

11. Self-advocacy. Ability to express one's needs to elicit help on a daily basis from others in a position to

provide assistance, from such people as health care practitioners, bus drivers, grocery clerks and police officers.

12. Self-esteem. Satisfaction of or respect for oneself.

13. Work behaviors. Any action or conduct exhibited while working in a competitive job which affects the performance of that job. Included are time management while working, ability to maintain working relationships with co-workers and supervisors and the ability to initiate and stay on task.

Assumptions

During the course of this study, the researcher makes several assumptions. The first assumption is that positive relationships exist between competitive employment and the other components of a person's life, and that these relationships can be identified. Once observed, these attributes and skills can be used to enhance the subjects' lives.

A second assumption is that the acquisition of competitive work is a milestone for an adult with mental retardation. Once accomplished, an individual may move on to a more independent lifestyle, thus becoming a valued member of society.

A further assumption is that an adult with mental retardation will move toward meeting set expectations. If socially acceptable behavior is expected, then high expectations will generally be met or exceeded. Conversely, if a person is labeled "low functioning," that expectation will also be realized.

The researcher also assumes that the exploration of factors affecting work and non-work components of a retarded adult's life could alter the way work skills and other functional activities are taught to people with mental retardation.

Limitations

The researcher could find no evidence of prior research concerning the effects of competitive work on the non-work life of the adult with mental retardation. Therefore, this will be a pilot study. Findings from these case studies will not be generalizable to other people with similar characteristics.

The study is not including as subjects, individuals with mental retardation who are employed in any settings other than competitive employment. Many people in sheltered employment, industry supported enclaves, and other forms of supported employment may experience similar situations and share like impressions.

This study will not consider people with developmental disabilities such as cerebral palsy, or those who are non-verbal which will further limit the study.

Finally, bias on the part of the researcher, significant others participating in the study, and subjects may skew the results of the study.

Significance of the Study

There is limited evidence of research that addresses the effects of competitive employment in the non-work life of adults with mental retardation. It is not known whether factors which make a person successful in competitive employment may be generalized to other areas of life, thus encouraging further successes.

Identified strategies and perceived "variables" may be duplicated by therapists, job coaches or caregivers who assist adults with mental retardation to have improved quality of life during work, leisure and self-care.

Through documentation of positive and negative effects of competitive employment on leisure and self-care roles, a foundation can be established for occupational therapists and other service providers which may enhance or change training modalities and approaches used with adults who are mentally retarded as this unique group strives to become productive members of the society.

CHAPTER 2

REVIEW OF THE LITERATURE

This literature review initially defines mental retardation, presenting various perspectives commonly used by practitioners who work with people who have mental retardation. Next, the review describes the historical and current status of the move toward placing adults with developmental disabilities in competitive employment. Included is a discussion of the effects of agricultural and industrialized society on the employment of members of society with disabilities, social and other phenomena which affected the ability of people with disabilities to participate in society. Next, the value of work as viewed by occupational therapy theorists and others is presented, followed by discussion of the interrelationships between work, self-care, and leisure. Finally, the conceptual frame of reference is described.

Mental Retardation

People with mental retardation have decreased intelligence or intellectual processors used to acquire behaviors. The most widely accepted and used definition was developed by the American Association on Mental Deficiency (AAMD): "Mental retardation refers to significantly

subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period birth to 18 years of age" (Grossman, 1973, p. 11). The AAMD goes on to classify levels of mental retardation based on intelligence quotients gleaned from standardized intelligence tests (Halpern, 1981). An individual may be classified as mildly, moderately, severely or profoundly mentally retarded.

Many authors reviewed report that the AAMD definition is harmful when used by itself (Evans, 1983; Halpern, 1981; Neisworth & Smith, 1978). Evans (1983) views mental retardation from what he terms a "common sense approach." He uses a functional definition with three points: first, people with mental retardation do not learn as quickly as non-retarded people; second, people with mental retardation do not store information as well as non-retarded people; and third, people with mental retardation do not have the ability to use abstract thought which makes it difficult to generalize information from one situation to another.

Evans (1983) presented four perspectives of mental retardation. The biological, mental, behavioral, and social role perspectives will be described in detail. The biological perspective, which is a traditional perspective calling upon biological definitions related to abnormal physiology or anatomy as reasons for mental retardation.

This perspective encompasses all disorders which physically could cause retardation such as gross brain disease, chromosomal abnormality, trauma and others.

The second perspective is the mental perspective which is divided into two orientations; the developmental and deficit models. The developmental model postulates that a person with mental retardation functions like a normal person of a lower chronological age. Therefore, mental retardation means a person has the normal intelligence of a normal, but much younger, person. The second model under the mental perspective is the deficit model. The deficit model maintains that the lower the intelligence quotient, the less adequate the mental processes. People with mental retardation differ from normal, younger persons with the same mental age because they lack the intelligence and thus adequate mental processing.

The behavioral perspective defines mental retardation as the absence or inadequacy of behavior skills and techniques. Society sets guidelines for behaviors that are considered normal and abnormal. Behaviorists believe people with mental retardation are set apart from "normal" people by their limited behavior repertoire.

The fourth perspective is social-role perspective which maintains that mental retardation is a "devalued" status placed on certain individuals. "Abnormal" behaviors are

labeled as such by a "labeler," or member of society designated to classify people's behaviors. The "labeler" must be willing to place the retarded label on a person. The last condition to be met is that a person must be unable to perform appropriate and socially valued behaviors.

Willard and Spackman (1983) refer to "composite classification," taking into account the AAMD definition, use of IQ scores, etiological factors with prognosis, a current adaptive behavioral status and educational level status to plan occupational therapy for a person with mental retardation.

History of the Work Movement

Editors Kiernan and Stark (1986) assert that the move from a frontier and agricultural society to an industrialized one resulted in greater specialization and separation of activities for the individual worker. This move resulted in less interaction between a person's work, residential and social spheres. Money replaced the barter system and work gained a greater status financially and socially. Maintaining independence became more difficult if one didn't have a job outside the home, and during this time the unemployed status became less socially acceptable.

Social acceptance also became more difficult for persons with disabilities during the industrial age for a

variety of reasons according to Kiernan and Stark (1986). Emphasis was placed on productivity and technology which made employment opportunities less available to individuals with disabilities. Value was placed on greater mobility residentially and to secure adequate employment. Workers were increasingly expected to have greater flexibility within their jobs. Independence in lifestyle with decreased support of the extended family became more highly valued.

During World War II and at other times of high demand with a reduced labor force, persons with disabilities moved into the employment market. Sheltered workshops were developed and thought to be the most viable vocational option for adults with disabilities. Industry could subcontract with the workshops for inexpensive labor, without having disabled workers mainstreamed in the main labor force. During that time non-disabled workers were separated from workers with disabilities which limited interaction in work, social and residential spheres. Large institutions began to replace extended family units as persons with disabilities residential needs were readily met, when nuclear families were becoming more mobile (Kiernan & Stark, 1986).

During the 1950s, normalization as a concept was developed in Denmark. Normalization was brought to the United States through Wolf Wolfensberger. Bank-Mikkelsen,

the creator of the philosophy of normalization believed that people with mental retardation should live life as normally as possible. As the system of large institutions and sheltered employment began to prove ineffective, alternative methods were developed with normalization concepts at the center of the movement. Industry supported enclaves, supported employment and competitive employment were a few of the employment alternatives. Community residences, supported apartment living and independent living models became residential options in addition to institutional living (Wolfensberger, 1977).

The Value of Work

Substantial literature was found concerning the value of work in people's lives, maladaptive cycles that occur when work is unobtainable, and how lack of work effects performance in non-work areas. Literature will be presented concerning skills and attributes that are generalized into work and non-work work areas of people's lives.

Matsutsuyu (1971) suggested that the act of choosing an occupation can only be accomplished after gaining mastery and competence, evident through a person's understanding of his/her own resources, those available through the environment and opportunities found in the family, community, and corresponding availability of jobs. Gaining

an occupation also "speaks for the cumulative effect of childhood play and chores, through exploration of mastery to practice, of a variety of skills in the performance of everyday behavior" (p. 291). Many adults have not been accorded the chances to engage in "normal" play, chores, nor have they experienced skill master at any early age. Once engaging with competitive work, these adults may have different responses which are also transferred into their non-work lives, given their atypical development.

Kielhofner (1980) summarizes the work component's importance in adult life. Work is the focal point of an adult's life, ordering and adding consistency to the "daily life pattern." Work is "a major source of personal satisfaction if the adult is able to usefully employ and expand his or her interests and abilities" (Kielhofner, 1980 p. 662). Work provides a purpose for one's life and because so much of life is spent working, attributes observed while a person works may also be observed during non-work activities. Persons who have experienced personal satisfaction through work may likewise seek the same positive feelings during non-work hours.

Satisfaction gained from work is part of a cycle, involving other components of non-work. Successes experienced while working are likely to encourage skill acquisition and knowledge leading to further successes

(Kielhofner, 1980). "If the person comes to believe in his own efficacy - to have generalized feelings of competence - he is likely to see and seek out opportunities and to try" (Kielhofner, 1980, p. 733). One of the places a person is able to experience success is while working, but mastery leading to success also needs to occur in other areas of life. Adaptation and success are sought after in an attempt to meet demands of the environment (Kielhofner, 1980).

Halpern, Close and Nelson (1986) refer to employment "...as the glue that holds a person together. The activities of preparing for work, commuting, producing, interacting with co-workers and supervisors, earning a living are hallmarks of successful adjustment" (p. 74). The authors assert that people with developmental disabilities who secure adequate and stable employment have necessary job and social skills before seeking competitive employment. Workers living with their families were most often more successful in competitive employment than their counterparts living in apartments alone.

Interrelationships Between Work, Leisure and Self-Care

Martin (1988) described domestic and community access skills required to insure success in independent living. Mobility, including pedestrian, bus riding and car driving, high level activities of daily living such as money

management, banking, food purchasing in stores, restaurants and from vending machines, using a telephone, securing emergency services, meal preparation, housekeeping and self-medication were some skills considered by the author as being critical for independent living. Martin believes that compensating techniques provide ways to insure that tasks may be completed even when an individual may not be able to complete the task his or herself. "When individuals are able to do these steps in conjunction with learned community and domestic skills, they should become more successful at community living" (Martin, 1988, p. 169).

Summers (1986) describes "critical skills" similar to those identified by Martin. Summers asserts that for adults with developmental disabilities, attainment of financial resources can increase their ability to utilize community resources. Thus, quality of life is improved and adults with developmental disabilities may purchase assistance when skill levels aren't high enough to permit independence. Financial remuneration resulting from competitive employment may insure competency in non-work areas. Individuals may also participate in activities with earnings from competitive work increasing living and social options (Kiernan & Stark, 1986).

Fidler and Fidler (1978) contribute to the perception that "to do" can be verification of a person's competence,

control or non-control over self and the external environment. When people cannot take care of themselves, inability to effect the environment is realized, thus they feel their incompetence. This cycle leads to maladaptive behaviors as the person seeks a way to gain control over his/her environment. In addition, the authors make reference to the "meaning and worth" of mastery or one's doing. "Doing" takes on new significance when valued by significant others. Self-esteem is the result of positive feedback from others upon the achievement of mastery in a particular area of "doing." In this way mastery of an occupation which is valued by significant others can result in increased self-esteem which may be generalized to non-work areas.

People's lives may be divided into three spheres; vocational, social and residential. These areas must be attended to simultaneously. Events such as changes in living situations or lack of social outlets may lead to the termination of competitive employment. This is the result of the worker's inability to perform on the job because of the disruption in non-work spheres. Adults with developmental disabilities must have harmony in all spheres to maintain competitive employment (Kiernan & Stark, 1986).

Diasio (1978) in her Larger Environmental Systems diagram shows four major spheres of rest/sleep, daily life

tasks/ADL, leisure/self actualizing activities and finally work. The four spheres merge together, interacting across vague boundaries. Therefore skills needed for leisure might also be used to master work and activities of daily living. Attributes such as self esteem and the ability to self advocate, used to gain competence in occupational roles would also cross the boundaries of the four spheres (Diasio, 1978).

The greater the number of occupations a person is able to master, the greater the opportunity to master the external environment (Reed & Sanderson, 1983). The authors also make reference to building a lifestyle which supports the balance of self-maintenance, productivity and leisure. The balance differs with each individual, but failure to achieve basic functioning in any of the three occupational areas leads to maladaptation and the acquisition of an unhealthy lifestyle (Reed & Sanderson, 1983).

Frame of Reference

The occupational performance frame of reference delineates three areas of functioning in a person's life; self-care, work and leisure. Corresponding performance components include sensory, motor, psychological, social and cognitive functioning. Once disrupted by atypical events such as a developmental disability, a person's ability to

gain new skills and generalize learning may impede success in self-care, work and leisure roles. Occupational therapists have traditionally served to facilitate learning, compensation and skill acquisition in desired life roles (American Occupational Therapy Association, Inc., 1974).

Occupational therapists are aware of skills and attributes required to be successful in life roles. By using specific interventions to improve functioning in each performance component, therapists can assist adults with developmental disabilities to become successful in self-care, work and leisure.

Summary

The literature on mental retardation described four major perspectives: the biological, mental, behavioral, and social role perspectives. A composite classification by Willard and Spackman (1983) provides a functional perspective from which to plan occupational therapy to include work as treatment. Work is described as normalized activity (Kiernan & Stark, 1986; Wolfensberger, 1977). According to Kielhofner (1980), work is an important component of a person's life. The occupational performance frame of reference includes work as a functional aspect of occupational performance that provides meaning in everyday life (American Occupational Therapy Association, 1974).

Systems perspectives described the possible relationships between work and other life tasks (Diasio, 1978; Reed & Sanderson, 1983). The literature revealed no studies of the effects of normalized employment on the lives of adults who have mental retardation.

CHAPTER 3

DESIGN AND METHODOLOGY

Purpose

The first purpose of this study was to explore if there were observable and self-perceived associations between the acquisition of competitive employment and quality of life for adults who are mentally retarded.

The second purpose of this study was to attempt to describe skills and work behaviors of subjects. Skills include any capability a subject must have to complete a specific competitive job, and the ability to maintain and increase competitive skills. Work behaviors included time management on the job, the ability to establish and maintain interpersonal working relationships with co-workers and supervisors, and the ability to initiate and stay on task.

Design

This study was conducted using a case study design. Individual subjects and their significant others participated in extended interviews designed to yield data about pre and post competitive work lifestyles. In addition, subjects were observed while working, during leisure pursuits, and while engaging in self-care tasks.

Questions

This study attempted to answer the following questions:

1. What are the differences perceived by persons who have mental retardation in their ability to be successful in non-work activities before and after engaging in competitive employment?

2. Which work behaviors learned at competitive jobs do individual adults with mental retardation and their significant others report as having an effect on their non-work lives?

Subjects

Subjects were identified with the assistance of staff from work training programs in Butte and Sacramento counties which serve people who have developmental disabilities in Butte and Sacramento counties. The researcher made the phone contact with several agencies in an effort to locate subjects.

Criteria for subject selection were as follows. Subjects must have been over twenty-one years old and have had no physical impairments such as cerebral palsy. Subjects were required to have been competitively employed at least three continuous months prior to participation in the study, and have verbal ability adequate enough to answer interview questions. Subjects were required to have a

formal diagnosis of mental retardation with verification by a California regional center, and not be dual diagnosed as having mental illness in addition to mental retardation. Finally, subjects were required to identify a significant other person who knew the subject well enough to answer interview questions regarding pre and post competitive work behaviors and habits.

The subjects were five adults with diagnosed mental retardation, who were over twenty-one years old. Two subjects resided in Butte County, California and three subjects lived in Sacramento County, California. Subjects in this study resided in board and care homes, at home with relatives or in independent living arrangements (alone in an apartment). Each subject in this study had worked competitively for at least three months prior to participating in the study. Subjects were employed in landscape maintenance, office work and janitorial services. Each subject was a verbal adult who had received services, or were currently receiving services through the Far Northern or Alta California Regional Centers. Subjects were not physically impaired, and none were dual diagnosed as having a mental illness in addition to mental retardation.

The subjects' "significant others" were people who knew the individual subjects long enough to respond to questions concerning pre-work lifestyles and attitudes and behaviors

of their subjects. Significant others included relatives, sheltered workshop staff, board and care operators and personal friends. Significant others were first informed of the study through the subjects and subsequently were contacted by the researcher.

Methodology

Each of the five subjects completed an informed consent form (Appendix A), completed an extended interview (Appendix B), were observed by the researcher during self-care, leisure and while working. Observations were written in narrative style using the observation form (Appendix C).

"Significant others" also completed an informed consent form (Appendix D), and participated in an interview (Appendix E).

Procedures

Subjects were interviewed using extended, open-ended questions to introduce general topics to be discussed (Appendix B). Areas explored during this interview included relationships with other people at work, home and during leisure pursuits, self-esteem, overall motivation, ability to care for self and living space. Prior to each interview, permission was obtained from subjects to have responses taped recorded. Following each interview, the interview was

written on the interview form (Appendix B) in narrative style.

Following the interview, each subject was observed by the researcher during leisure, self-care (generally in home and environment) and while working. Observations were recorded on the observation form (Appendix C).

The subjects' "significant others" were interviewed using an interview form (Appendix E). The interview was tape recorded, after receiving permission from significant others and responses were later written. Questions asked of significant others were designed to be used as general topic outlines to address self-care abilities, leisure interests, self-esteem, ability to problem solve and personal and work relationships with other people before and after the acquisition of competitive work.

Data Analysis

The data were organized by individual case studies. Interviews of subjects and their significant other people were audiotaped and the information was transcribed onto interview forms following each interview. Interviews were reviewed to insure that questions and information had not been overlooked. Each subject was observed during leisure time, as they completed self-care and household maintenance, and while working. Written notes were made by the

researcher during the observation. Following each observation, notes were rewritten in a narrative form on an observation form (Appendix C). Each case study was written to provide information in the following areas: identification information, daily schedule, work history, current work status and observation information; social and activities of daily living history with current status and observation report. Next the significant other person interview was reported, followed by a short summary of the case study.

The researcher analyzed the content of the interviews and observations to determine whether links existed between variables which may have influenced the non-work lives of people with developmental disabilities employed competitively.

The researcher attempted to identify common trends in the data as described by the subjects, subjects' significant others and/or observed during data collection.

CHAPTER 4

DATA AND RESULTS

Each case study will be presented using fictitious names for subjects and their significant others. Case studies will be presented, describing the following: identification information; daily schedule; work history, current status and observation; social and Activities of Daily Living (ADL) history, current status and observation; significant other interview; and summary.

Next, the results of the study will be presented to answer the research questions. Results of the study are based upon responses received during interviews with subjects and their significant others, and during observation of subjects as they engaged in work, self-care and leisure activities.

First Case Study

"Lea"

Identification Information

Lea is a 24-year-old woman who lives in a two-bedroom apartment with three other people. One of her roommates is the boyfriend whom she has been with for one year. She receives services from the Far Northern Regional Center and is considered to be mildly mentally retarded. Lea's family

lives in Oregon and she has limited contact with them. Lea is employed as a landscape maintenance person in a city park.

Daily Schedule

Lea wakes up at 7:00 a.m., and gets out of bed, combs her hair, eats breakfast and catches the bus for work to be there by 8:15 a.m. At the time of the interview, Lea had just moved to a new apartment and was unsure how she would get to work on the bus. Lea works four hours per day, then catches the bus to return home to her apartment. She has no set place to eat lunch and often does not eat this meal. Lea reports that she spends most afternoons cleaning the house and cooking dinner for her roommates. Lea watches television, plays a board game or "parties" until she goes to bed between 12:00 a.m. - 1:00 a.m. Lea likes to "sleep in" on weekends but could think of no other differences between activities on weekends versus workweek days.

Work History, Current Status, and Observation

Lea recalls graduating from high school. She had difficulty with reading and math but was able to pass these subjects with the help of special education classes. Following high school, Lea was referred to a supported work program. She worked with six other peers and one crew

leader learning outdoor maintenance including lawn mowing, pulling weeds, picking up garbage and edging lawns. Lea stated that she also learned to fill out a time card and learned to use the transit system instead of the "handicapped" bus system. Lea stayed on this work crew for two years before she was placed in a sheltered workshop because of personality problems with workers in her crew.

At the workshop Lea performed assembly work interspersed with ceramics classes. She reported being bored by both of these activities and continued to get into fights with peers. Lea feels these difficulties were caused by her being "less retarded" than the others at the workshop. Lea also felt there was too much time to "sit around and do nothing."

Lea remembers being invited to join the competitive work program. She went through three jobs before finding her current job. The other jobs were too difficult for her. She was able to offer little insight into what tasks were too difficult, or why some jobs were beyond her ability.

Lea has been in her current position as a landscape maintenance worker for two years. She mows the lawns using a push mower, edges the lawns, cleans the bathrooms and washes down the tennis courts. Lea believes that her strongest task performance is mowing lawns, although it is also the most tiring job for her. The task with which she

needs the most assistance is bathroom cleaning. Her job coach checks on Lea's job performance two times per week. Lea likes her job coach because she gives advice on how to work, and occasionally helps Lea with her work.

Lea was observed by this researcher to require constant prompts to remain on task while cleaning the public bathrooms at the park. The park manager, who was also Lea's boss, checked on her every half hour to make sure Lea was working. She managed the lawn mowers and edgers without problems, but complained consistently about being fatigued. Lea's supervisor was patient while pointing out ways for Lea to make her job easier, prompting her to keep working. Lea would take breaks to smoke cigarettes and lay in the grass, and needed prompts to return to work. She appeared tired and disinterested during much of the time this researcher observed Lea's work performance.

Lea stated that she likes being employed competitively because she earns money and does not have to be around as many people as she was in the sheltered workshop. Lea felt she learned many skills at the sheltered workshop, for example, getting to work on time.

Social and ADL History, Current Status, and Observation

Lea lived with her parents through high school and was placed in a board and care home. Lea recalls that her

parents did not want her to continue living with them so they asked the regional center to find a home for her. About that time, Lea was beginning to earn a small salary from her supported work job. She was excited that when she lived at the board and care home, Lea could spend her earnings to buy fast food.

Lea described herself as being self-taught in such skills as money management, washing laundry, and preparing meals. After reflecting, Lea admitted that staff at the board and care also taught her "a few things."

While living in the board and care home, Lea had meals prepared for her, but was expected to keep her room clean, independently complete self-care, travel to and from work and arrive at meals on time. Lea lived in the board and care home about three years before her regional center counselor asked Lea to consider moving to her own apartment.

Lea moved into an apartment with her boyfriend. She met her boyfriend at the workshop shortly before becoming competitively employed. The regional center provided a life skills worker to assist and train Lea in household maintenance, meal preparation, shopping and money management. Lea reported that the life skills worker sees her four hours per week and actually assists with housework and shopping.

Lea reported that she has difficulty managing household tasks. Lea's self-care and other ADL were observed as Lea completed these tasks. As with work, Lea was unable to move through an entire task without resting and smoking. She frequently complained of being tired. Lea independently bathes and dresses, but had an ill-kept appearance when observed. She looked as if she had just gotten out of bed. She appeared to have an impaired ability to plan the sequence to accomplish more difficult tasks such as making hamburgers. Lea turned the burner on under the frying pan before she had gotten the meat out of the refrigerator and prepared the meat patties. When questioned about the safety of this practice, Lea said she had forgotten the burner was on, and told a story of the fire department coming to her apartment another time when her burner was left on.

Lea believes that her greatest social problem is getting money back from friends, after loaning them money. She has a set group of friends outside of work. Lea does not see any workers from her job outside of work, and since she works alone, rarely has opportunity to socialize at work. Lea prefers to socialize with her roommates and boyfriend.

Lea does not see her parents as they do not like her boyfriend because he is black and she is white. She believes her parents are prejudiced, and added that while he

may drink some, he never "beats her up." She was observed with her roommates and boyfriend during an evening at home. They were mostly nonverbal, although did talk about Lea's job and meal possibilities. Lea spent much of the evening watching television with her friends. They mentioned that they occasionally take the bus to the movies when they collectively have enough money.

Significant Other Interview

Lea chose Janice as her significant other person to be interviewed. Janice is employed by the sheltered workshop with the competitive work program component. Janice has known Lea since she entered the workshop program and has watched Lea progress into the competitive work program. Janice now acts as a case manager on Lea's behalf as she works at her job.

Janice believes that Lea will always need a life skills counselor to assist with money management and to insure that Lea's boyfriend and roommates do not take advantage of her. She believes that Lea is using drugs and feels that the life skills counselor must keep up with Lea's personal situation.

Janice stated that Lea "has come a long way," showing increased responsibility on her job, more frequently being consistent in her job performance. Lea has also shown increased adherence to pre-employment skills such as getting

to work on time and wearing appropriate clothing. Lea regularly required reminders to wear appropriate clothing to the sheltered workshop, but has never been sent home to change clothes since becoming competitively employed.

Janice was concerned that Lea does not have a chance for more social interaction at work. She feels that Lea is not mentally disabled enough to benefit from special leisure programs, but Lea does not have the social skills to relate to non-disabled people. She adds that Lea "runs with a questionable crowd" and that she is rarely away from her boyfriend and roommates when not at work. Janice does not see Lea as having changed socially since being competitively employed except that she fights less.

Janice has observed that Lea uses more safety judgment in her job than she did in sheltered employment and that Lea has more understanding of money use and budgeting since becoming employed. Although Lea's grooming skills are not as developed as those of a normal peer, Janice commented that Lea seems to take better care of her person since she became employed.

Overall, Janice believes that Lea is a person who is "at risk" both in her job and personal life. Lea will not be able to live independently without assistance for some time, and will remain competitively employed only as long as

her job supervisor is willing to give her "special" help and consideration.

Summary

Lea lives independently with her boyfriend in an apartment and is employed in landscape maintenance. She uses public transportation for translocation to work, for leisure activities and to shop. She is a high school graduate with supported work experience following graduation. While in the supported work program, Lea learned several pre-employment skills which she uses in her current job such as completing a time card.

Lea held three jobs previous to her current position, since becoming competitively employed. Most jobs were considered too difficult by Lea. She receives job techniques advice and physical assistance, and checks each half hour from her boss in her current job. Lea required prompts to remain on task, return to work following breaks and appeared fatigued and disinterested in her work.

Lea had an ill-kept appearance when observed and could not identify basic relationships between self-care and employment when questioned specifically about this during interviews. Lea receives support services from a life skills counselor who assists with household maintenance and high level activities of daily living such as shopping.

Lea has a few leisure time pursuits such as going to movies or out to eat. She has difficulty keeping track of her money, especially after making loans to friends.

Lea's significant other person, "Janice," believes that she is involved in drug use. Janice believes that Lea will always require assistance to maintain her independence in the community. Janice reported that Lea has increased in her ability to get to work on time, wear appropriate clothing, and is fighting less with other people since becoming competitively employed. Janice believes that Lea will be competitively employed as long as her job supervisor is willing to give her special support, beyond that which a nondisabled peer worker would receive.

Second Case Study

"Larry"

Identification Information

Larry is a 37-year-old man who is described by the Far Northern Regional Center as having mild mental retardation. He is a personable, attractive individual who has been competitively employed for ten years. Larry currently works as a janitor in a large dinner restaurant. He is the fourth of five children and enjoys the support of a large family. Larry lives alone in a mobile home located in a mobile home park.

Daily Schedule

Larry typically begins his day between 5:30 and 6:00 a.m., getting out of bed and preparing a simple breakfast of cold cereal. He dresses carefully and completes morning grooming, working slowly and thoroughly. Larry washes his breakfast dishes and drives to work in his new truck.

Larry arrives at work in time to open the door at 7:00 a.m. He leaves his job at 12 noon. He enjoys eating lunch at a local cafe, but does not know any other regular patrons at the cafe. Often, Larry will sit and drink coffee after his meal. Following lunch, Larry returns home or runs errands. He had difficulty describing his errands, but thought this might include buying gas or food.

After returning home in the afternoon, Larry watches television, cleans his house, or paints with oils. He begins to prepare dinner around 5:30 p.m. and reports that regular mealtimes are important for him. He eats dinner while watching television and continues to view television most of the evening. Larry retires to bed between 10:00 and 11:00 p.m.

Larry has just started a second part-time job a few evenings per week. He assists with dinner preparation at a nursing home, arriving home around 7:00 p.m. On those nights, Larry eats dinner at the nursing home.

Work History, Current Status, and Observation

Larry graduated from high school at age 20, after which he entered a day activity center and independent living program. Larry recalls that these programs taught money management, meal preparation and pre-employment skills. Larry was placed in the program by his regional center counselor, and feels this program helped him maintain basic skills and learn community survival skills. One year later, Larry was referred to the Department of Vocational Rehabilitation by the regional center and was placed in a sheltered workshop.

While employed in the sheltered workshop, Larry performed assembly line contract work, bagging plasticware for airline use. Later he was placed in a thrift shop as part of the sheltered workshop contract. Larry unpacked boxes and stocked shelves with several peers from the workshop. The contract was terminated and Larry left the workshop to attend junior college. Larry enrolled in the disabled student's program at the junior college and began volunteering in the activities department of a convalescent home. Although he never graduated from college, Larry described the experience as positive. He learned additional independent living skills, and math for money management. Larry continued to volunteer at the nursing home for six years and was offered a job as dishwasher a few nights a

week. He left the area and again went into sheltered employment.

Larry was referred to a workshop that has supported and offered competitive work components. He was placed in the competitive work program where he worked several short-term jobs. All were service-related and tasks were janitorial in nature. Larry was told by his job coaches that he handled simple jobs such as bathroom cleaning and floor care easily. Larry was referred to his current job two years after starting in the workshop. Larry has worked in his current position as a janitor in a restaurant for 2-1/2 years.

Larry vacuums the dining room, cleans the bathrooms and dusts the furniture. He receives minimum wage with health benefits as compensation. Larry works independently and receives weekly visits from his job coach. He has a key to let himself into the restaurant and works alone until other employees arrive around 10:00 a.m. Larry has little social interaction with other employees. The people that begin work mid morning are cooks, the accountant and manager of the restaurant. Since Larry is the janitor, it seemed natural and appropriate that he would not have much opportunity or reason to relate extensively in a social manner.

Larry follows a set routine to complete his job. He varies little day to day, beginning with cleaning the

bathrooms and ending with dusting the furniture. He relates to each task as a series of steps, reflecting the training he received when the job began. Larry worked consistently through interruptions such as speaking to his boss or other situations which caused a break in his routines. While being observed, Larry required no cues to stay on task or return to work. He used adequate technique to complete the job and required no prompts to complete work not satisfactorily finished. Larry answered questions regarding reasons for doing his job certain ways. For example, when asked why he used a specific cleaner in the bathroom, Larry replied that the cleaning agent "kills germs."

Social History, Current Status, and Observation

Larry has always enjoyed social support provided by his family and frequently visits his parents. He helps in his parent's large garden, eats often at their home and does his laundry weekly. While he visits his parents in their home, he rarely visits his siblings in their homes.

Larry is minimally involved with the adaptive leisure program. He views himself as being "caught in the middle." Larry does not feel as disabled as the program's regular attendees, but has not been able to find friends who do not have mental retardation. Larry reflected that he has had friends from work in the past, but now attributes his lack

of friends to "being too busy" with two jobs and an active family life. Larry was unable to describe how he would meet or date a person in whom he was especially interested. He does not attend dances, go to nightclubs or church where a special friend or partner might be found.

Larry enjoys window shopping, oil painting, and watching television. He drives around the downtown area just to "see what is going on." All are solitary leisure pursuits which Larry says he prefers.

Larry was observed during a potluck meal sponsored by the adaptive leisure program. He conversed easily during social introductions to peers but became aloof following initial interactions, preferring to observe events around him. Larry interacted more when the event was goal directed than during situations where he was expected to interact spontaneously. Outside of his family, the adapted leisure group offers the most opportunities for Larry to socialize. Larry acted as if he felt like a fringe member of the group with which he most often socializes outside his family.

Significant Other Interview

Larry selected his mother as his significant other person to participate in the study. She described Larry's involvement in competitive employment as a part of a developmental sequence. Larry had always been encouraged by

his family to work, live separately from them and manage his own affairs, seeking assistance only as needed.

Mrs. Q (Larry's mother) reported that Larry has always had a difficult time managing money and that he required assistance to balance his checkbook. Over the past few years, Larry has learned to seek assistance from his bank to keep his account in order. Mrs. Q feels that Larry has learned to approach other people outside his family for assistance. He readily talks to his boss about work problems.

Larry has always been meticulous in his basic self-care, preferring to dress fashionably and learning whatever skills were necessary to maintain his appearance. Larry taught himself to iron in high school and was independent with bathing, grooming and dressing at an early age. Mrs. Q believes this quality set him apart from other workers in the sheltered workshop and may have been instrumental in Larry's being selected for the competitive work program.

Mrs. Q related that Larry was always on the "outside," skill-wise and socially while in sheltered and day activity programs. Larry lacks some of the skills necessary to advocate for himself and continues to need significant support from others. Two years ago Larry had a roommate who began stealing Larry's money and using drugs at home. Larry's parents contacted the regional center to have the

roommate removed. Mrs. Q believes that Larry would deal more effectively with this situation today as he is more comfortable asking others for assistance.

Mrs. Q has observed Larry doing his job. She sees the same sense of order that is used at his job being employed in Larry's personal life, in daily routine. For example, Larry uses the same cleaners in his home as at work. Mrs. Q believes Larry's skill repertoire has grown since being competitively employed. She sees Larry handling social situations with greater flexibility, but has yet to hear Larry speak of a girlfriend or constant good friend. She is sometimes concerned that change in Larry's life has always been managed by outside forces such as family and social services. Mrs. Q would like Larry to begin stating his preferences and create his own changes.

Summary

Larry works as a janitor in a restaurant and lives alone in a mobile home. He owns and drives a new truck to work, when running errands, and to visit family. A high school graduate, Larry has worked competitively for several years. He has been through sheltered workshop and supported work programs. Larry was observed to be independent while completing job tasks, as he is while completing household maintenance.

Larry visits his family frequently and is not actively involved with adapted leisure programs. He reports no close friends, but engages in solitary hobbies such as oil painting and watching television.

Larry's mother, Mrs. Q, reported that he was always independent for self-care, but continues to require assistance to manage money and to act as a self-advocate. Mrs. Q reported that Larry's skill repertoire has grown during the years of competitive employment, but is concerned by his inability to take charge of his life.

Larry has learned to manage his time between two jobs, manage his home and maintain close family ties. Most of his leisure pursuits are solitary. He has attempted to socialize at events sponsored by the adaptive leisure group, but sets himself apart and feels he is not as "disabled" as other members of the group.

Larry has generalized some cleaning techniques used at work into the way he cares for his own home. He also realizes that with increased income his life has changed. Larry purchased a truck, eats out more often, pays rent and can afford his oil painting hobby.

Third Case Study

"Mike"

Identification Information

Mike is a 23-year-old man who lives with his father, stepmother, and one brother. The Alta California Regional Center described Mike as having mild mental retardation. Mike has received extensive job training through an agency that specializes in supported and competitive work training. He is currently employed in a large medical center in the housekeeping department.

Daily Schedule

Mike gets out of bed at 5:30 each morning, fixes a simple breakfast before driving himself to work. He arrives at work at 7:00 a.m., and eats lunch at 11:00 a.m. Mike leaves work at 4:00 p.m. He stops at a fitness center to "work out" on his way home. He "works out" for an hour before returning home to watch television. Mike eats dinner with his family and watches television after eating. He goes to bed around 10:00 p.m. On his days off, Mike runs errands, watches television and goes for walks.

Work History, Current Status, and Observation

Mike graduated from high school and was enrolled in mainstream curriculum for one-half of his classes.

Following high school, Mike went to work at Goodwill Industries, sorting and marking donations. Mike related that he had personal problems with other workers and left Goodwill after three months.

Mike had a series of jobs for the following six months, including selling light bulbs to businesses and working in a plant nursery. Mike did not like working in the nursery because the work was too "dirty." He thought the work would involve more floral arranging. Mike was then referred by the regional center to a vocational training program where he has been enrolled for four years. Mike has trained in a supported work setting in landscape maintenance and hospital housekeeping and janitorial work. He graduated from the supported work program after being offered a job in which he could work competitively following a training program with his job coach. He currently holds this job in the housekeeping department at a 500-bed medical center.

Mike has been working competitively for 13 months, increasing his job responsibility as he learns new tasks. He cleans windows and restrooms, changes sharps containers and has started to clean patient treatment areas in the emergency room. Mike relates to his job as a series of tasks. These tasks are broken into steps. Mike will speak of his job competency by the number of steps he has mastered. For example, he will relate that steps 1-13 are

well known, and that steps 13-20 have just been added.

Mike's job coach is available as needed, but Mike feels that most problems are solved by his supervisor who is the head of the housekeeping department. He feels comfortable in approaching his supervisor, evidenced by observation between his interactions with the supervisor.

Mike believes the biggest challenge on his job is ignoring people "that make me want to do violence to them." Mike reports that he works hard to avoid conflict using two techniques. The first strategy involves walking away from the person causing him distress. The second method is to report incidents to his supervisors. Mike reported that he has found these techniques useful in his non-work life, where he walks away from conflict that makes him feel physically aggressive. Mike also reports feeling comfortable talking with his regional center counselor about issues, and that he always feels better after "working out" at the gym. Supervisors encourage Mike to let provoking comments "roll off your back." Although conscious of the problem, Mike became visibly agitated when speaking of people making him angry.

Mike also has difficulty accepting limits and guidelines placed on him in the workplace. He feels that supervisors hold him back; do not allow him to progress in his job.

Mike was observed several times while performing on his job. He worked slowly, although consistently, paying close attention to detail. Mike stopped to greet people pleasantly who spoke to him first, but returned to work without prompts. He required no assistance for technique, follow-through or for use of equipment needed to do the job, for example, a wet to dry vacuum. Mike appeared to have adequate listening skills. He followed through with multi-step tasks at a supervisor's request. Mike was observed to have adequate support skills for employment such as promptness, wearing appropriate clothing, time management and efficiency.

Social, ADL History, Current Status, and Observation

Mike has kept several friends that he met while working in supported work enclaves. Occasionally, Mike has accompanied a "normal" co-worker to the fitness gym. Mike was unable to state how he would meet a woman to date, or where he would go outside of work to meet new friends.

During non-work hours Mike enjoys watching television, window shopping, and going to church. During warm weather Mike goes water skiing with his family. He currently has little social contact with people outside of work except his family. He was an avid churchgoer until he was required to work on Sundays. Mike attends services at the hospital

during work breaks. Prior to working Sunday, Mike was an active member of the church youth group.

Mike was observed while going out to lunch with a group of friends from work. All of the people in the group appeared to have developmental disabilities. Mike appeared to set himself apart from the group. He was asked about his job and all agreed they would also like to have a "real job." Mike was jovial with his friends. He spoke slowly and did not make eye contact while speaking. Mike gazed into space while smiling and speaking. He also sat a few chairs away from the group while eating, but did not appear to be embarrassed by his friends. Mike demonstrated acceptable functional, public behavior skills, for example ordering his food in a restaurant and eating neatly. He had a strange affect after he had finished eating and talking. Mike sat and stared into space. He did not speak or watch his friend talk. When Mike was not talking, he went into strange posturing until he thought of something to say.

Mike was unable to identify ways his non-work life may have changed since becoming competitively employed. However, since beginning his job, Mike has purchased a truck, started paying rent at his parent's house, and joined a fitness gym. Mike stated that he does not feel much different since becoming competitively employed.

Mike is as consistent and thorough with self-care as he was in completing his job. Mike believes that he has always been neat and clean, performing self-care independently at an early age. He washes his own clothes and irons them.

Mike uses a savings account to deposit and withdraw money to pay bills. He thinks money management is his weakest independent living skill. He has run out of money several times but now follows a step process similar to the technique used to learn a job skill, for learning money management. Thus far, he has mastered steps 1-12, having 20 additional steps to learn before managing his own checking account. Mike's main money management strategy is to make sure he has enough money before purchasing an item or service.

Mike plans to live in his own apartment within the next three years. He believes that he would require significant training to attain complete independence in shopping, meal preparation, and self-advocacy. Mike would also like to improve his social skills.

Significant Other Interview

Mike's stepmother, "Mrs. P" has known Mike since he was a small child. She reported that Mike has always been determined in making plans to have a job and live independently. "Mike has always been a worker," said Mrs.

P. He feels strongly about his work and advocates for himself almost "to the point of driving everybody crazy." Mrs. P tells the story of how Mike got his current job. The hospital kept promising him a "regular" job, outside the work crew, but was slow in actually giving Mike the job. A meeting was called with the hospital personnel, regional center counselors, parents, job coach, and Mike. Mike also called his state representative to report unfair treatment by the hospital. The political official sent a representative to make sure Mike was being treated fairly, much to the surprise of everyone sitting at the meeting. "We had no idea Mike had taken such strong action, but he also got his job quickly after that. We no longer underestimate Mike's ability to stick up for himself," said Mrs. P.

Mrs. P reported that Mike has had tremendous difficulty socially, especially in high school when he was a loner who wanted to have friends. She feels that Mike was perceived by high school peers as different, and feared Mike might be taken advantage of because he wanted friends.

Mrs. P is not aware of any friends Mike has outside work. She has heard about a possible girlfriend but, to her knowledge, he has not dated her. In the past, Mike has picked a "normal" co-worker up to go to work, or has gone to

the gym with some of the other housekeepers. However, these relationships have not yet developed into friendships.

Mrs. P has seen new interest in assisting with work at home since Mike began working competitively. He has always performed his personal care without assistance but needs significant assistance to manage money. "He doesn't seem to have any idea what money really means. He knows he can buy things, but has no concept of how to manage his funds," said Mrs. P. His parents spend significant time monthly with Mike to keep his account in order and teaching him to shop.

Mrs. P reported feeling that Mike deals honestly with problems and seeks assistance from appropriate people. "He used to tell everyone his problems, but is beginning to learn that that is not okay," said Mrs. P.

Summary

Mike is a high school graduate who had several jobs following graduation. He has been competitively employed at his current position as a housekeeper for 13 months. He lives at home with his family and drives his own vehicle to work each day.

Mike identified several strategies that he uses to control his behavior and to deal with people he dislikes while working. He works independently with occasional visits from a job coach. Mike performs his job slowly,

paying close attention to detail. He was observed to remain on task and completed job support tasks such as filling out a time card independently.

Mike maintains friendships with people in supported work programs, but sat a few chairs away from those friends during a social situation. Mike did not make eye contact in social situations and gazed into space while talking to people. He enjoys going to church and water skiing with his family, but has little social contact outside his work.

Mike completes his self-care independently and uses a savings account to manage his money. He needs assistance to manage his money effectively and is learning to shop and compare prices of items.

"Mrs. P," Mike's stepmother, describes Mike as a determined person. She reported examples of his ability to self-advocate to become competitively employed. Mrs. P believes that Mike has always wanted friends, but had difficulty actually making friends. She has observed that Mike has shown new interest in doing housework in the common areas of the family home since beginning his competitive job.

Fourth Case Study

"Roger"

Identification Information

Roger is a 40-year-old man who is employed at a fast food restaurant. He performs outside maintenance work and inside janitorial tasks. Roger lives in a semi-independent setting; a group home with four other men with one-third time staffing. The home is two blocks from a 16-bed board and care home, operated by the same owner. This is important because Roger eats all of his meals at the large board and care home. Roger has been identified as having mental retardation in the moderate range by the regional center. He is a tall, thin man, who wears clothes that are worn, and sometimes dirty.

Daily Schedule

Roger gets out of bed at 5:45 a.m. each day, dresses and walks two blocks to the large home for breakfast at 7:00 a.m. He generally arrives at the board and care home by 6:30 a.m. He waits in the living room until breakfast begins. Following breakfast, Roger assists with clean-up without being prompted by staff. He rides public transportation to work with two transfers required in the seven mile ride. He arrives at 9:00 a.m. to start his job. Roger's workday ends at 1:00 p.m. He takes the bus, or

occasionally walks back home. Once home, Roger will ask staff for tasks to do around home. He also watches television, listens to his radio, and/or walks to fast food restaurants to "hang out." Dinner is served in the big home at 5:30 p.m. Following dinner Roger watches television with his friends or goes back to his bedroom to watch television or listen to his radio. Roger generally goes to bed around 10:00 p.m. On weekends, Roger spends more time "hanging out" and buying hamburgers and other fast food at the local Burger King Restaurant. He watches television, listens to his radio, or performs additional chores for the board and care operator.

Work History, Current Status, and Observation

Roger does not remember anything about his formal education except that he was removed from special classes at age eight. Roger believes that he began janitorial work at that time, further claiming that he never went back to school.

Roger had been working in sheltered employment for no less than twenty years before being offered a chance at competitive employment. Regional center records show that he did a variety of jobs over the years, including nut and bolt assembly, outside landscape maintenance, and truck loading (lifting and hauling). Roger also had some day

activity components such as learning basic self-care skills, community integration training, social skills training and art classes. Roger was vague about his experiences in the sheltered workshop. He stated that he made good friends, most of whom lived with him.

Roger does not know exactly how or why he was offered a chance to work at the restaurant, but recalls going through an interview and requiring assistance to complete the job application. He began learning skills for his current job about one year ago when he received a full-time job coach. Roger started training a few hours per day at the restaurant until his time increased to four hours of work per day. Roger washes down outside driveways and parking areas, weeds the grass and landscaping, mops the restaurant floors and cleans the bathrooms. He described this work as "real work" and "man's work." Roger's job coach visits Roger and his supervisor, who is the manager of the restaurant, two times per week, staying about one-half hour each visit. Roger stated that his job coach does not do any work for him, but does provide suggestions about short cuts or different ways to do a task.

Roger feels he gets along well with his supervisor, calling him a "good man." He takes all his work problems to the supervisor. Most problems have to do with job mechanics as opposed to personal relationships on the job. Roger

stated that he gets along with co-workers because he has never fought with them.

Roger performs his job enthusiastically, exaggerating movements while sweeping and mopping. He worked independently but required checks on his work for thoroughness. Roger's supervisor reported that he checks each job after completion and that generally something needs to be re-done. The supervisor believes that Roger works too quickly. He is working with Roger on self-pacing to slow down and do better quality work. Roger demonstrated difficulty in staying on task, allowing interruptions to physically take him away from work. Again, the supervisor was very supportive, stating that he and a few of Roger's co-workers simply ask him to get back to work. This prompt level has been successful and the supervisor feels Roger is needing fewer prompts. "Roger enjoys listening to other people's business," reported the supervisor. He aligns himself with people at work who have the most information about other co-workers. Roger does not have difficulty with getting to work on time, but requires assistance every two weeks to complete his time card. The supervisor and job coach have requested that Roger get more appropriate fitting and clean clothes which the regional center is trying to work out with the board and care operator.

Social, ADL History, Current Status, and Observation

Roger reported that he does not see co-workers outside his job, socially, but that he has made friends with a police officer. The officer has a "beat" in the area where Roger lives and they visit while the officer is on duty. They have coffee together several times per week. Roger occasionally seeks the officer out at the police station, but does not like to disturb his friend while he works. He guards his friend from the other residents of the board and care, stating that he does not want the officer bothered by "other people." Roger enjoys talking about police work and sometimes thinks about becoming an officer.

Roger spends a significant amount of time with his roommates. He eats meals at the large group home. Since the stove has been broken at his house for two years, this situation provides additional socialization opportunities. He occasionally goes to a dance sponsored by the "special" leisure group. He looks forward to these dances which occur monthly. Roger stated that he does not dance, but likes to "hang out" and "mess around."

Roger was observed during several mealtimes and at one dance. He is a leader in his peer group. During meals he did not speak to his peers as if they were equals, but corrected information and directed the other men toward desired outcomes. If Roger perceived that staff was having

trouble with one of the other residents, he would correct the resident (peer) and staff would allow this to happen. Roger appeared to have an equal relationship with two other men with authority and with one other man who had a better television than Roger. He "messed around" with these three men during leisure times. These friendships appeared fragile at times with frequent fights followed by days of silence. Ritual amends were made by shaking hands, hugging and promises of never fighting again.

At the dance, Roger stood with several men in one corner of the room. Most were cohorts from the board and care. Occasionally Roger walked around and spoke to other people with short social greetings followed by silence unless information was shared about other people. Roger teased his friends about who they would dance with, but he never moved toward dancing himself. He appeared to enjoy the refreshments, consuming large quantities of cookies and punch, until prompted to stop by dance staff.

Roger was easily frustrated by his roommates. He raised his voice and called the men "dumb" and "stupid," but would leave the room rather than physically fight. He was observed to always get along better when he was in a position of authority with others following his recommendations and requests without question.

Roger showers independently every other day. He independently shaves, completes oral and hair care daily. Staff at the home wash his laundry and prepare his meals. Items for self-care are provided for Roger on a set schedule because he otherwise runs out of soap, shampoo and razors, frequently. Roger does not feel this is a problem, but does tell the staff when he is out of items. Roger had long, dirty fingernails, dirty hands and an overall unkept appearance. He attempted to look as clean as possible before going to work, especially if he spilled food on his shirt. Roger appeared to be aware of his appearance but had limited resources to look his best.

Roger had the same exaggerated movements while brushing his teeth, washing his face and showering. He sequenced tasks correctly but appeared to have poor fine motor skills while manipulating small objects.

Roger assists with cleaning the big house for extra spending money. The board and care operator receives Roger's money and provides Roger with small amounts for personal spending. Roger is required to give his paycheck to the operator. Roger was planning to talk with his regional center counselor about this situation. He has little money to manage except his personal allowance. Roger could recite prices from several fast food restaurants, make

change from a dollar and identify when he did or did not have enough money for an item.

Roger independently rides public transportation, having acquired this skill when he began the competitive work program. He has many prerequisite skills for bus riding; tells time and has a working watch, seeks out appropriate people for assistance, counts money and other skills.

Significant Other Interview

Roger admitted disliking "Mary," the board and care operator, but chose her as his significant other person. He has limited contact with his family and believed Mary knew him well, since he has lived in the home for seven years.

Mary perceives Roger to be a behavior problem when he gets excited or agitated; however, she feels Roger has gained more control over his impulses since getting his job. Mary believes this improved behavior may be the result of his not being around people that bother him. Mary expressed that Roger has more patience with his roommates since securing competitive employment.

Mary would like Roger to be employed full time, or go back to the workshop full time. She reported that Roger has too much time on his hands which permits him to get into trouble. With excess time, Mary thought Roger might get into fights or start "being around the house too much,"

although she admits this has not happened in the year that Roger has been employed.

Mary does not believe Roger could live independently, citing the inability to manage money or prepare meals, shop for groceries and his inadequate social skills for getting along with others as reasons. Mary stated that Roger could not survive on the salary from a fast food restaurant job because he would spend all of his money on eating out.

Mary thought that Roger has always been independent for self-care since living at the home. She believes that he has always needed guidance in his leisure life, when going to dances or other activities. She was unaware of Roger's friendship with the police officer.

Summary

Roger lives in a board and care home and works in a fast food restaurant performing outside maintenance and inside janitorial tasks. He was unable to relate an educational history and believes he started working as a child. Roger had been involved in sheltered employment for several years before going into competitive employment.

Roger describes his work as "real" and requires job coach assistance two times per week. He receives close supervision from the restaurant manager and other restaurant employees. Roger's work supervisor thinks he is needing

fewer reminders to stay on task. Roger requires assistance to fill out his time card, but arrives to work on time without difficulty.

Roger socializes with peers from the board and care he resides in, but does not see co-workers socially. He has made friends with a police officer, and visits at a local coffee shop frequently. Roger enjoys going to dances sponsored by adaptive leisure agencies, eating out in fast food restaurants, watching television, and "hanging out."

Roger was independent for basic self-care, but wore ill-fitting clothing. Roger used public transportation or walked for all community translocation.

"Mary," Roger's significant other person, believes Roger has more control over his behavior and increased patience with peers since he started his job. Mary sees little chance for Roger to live independently, manage his money, shop, or prepare meals without significant assistance. Mary believes Roger would benefit from being employed full time as there would be less time for him to "get into trouble."

Fifth Case Study

"Lisa"

Identification Information

Lisa is a 24-year-old woman who has worked in the personnel department of a large medical center for one year. She lives with her mother, father, and two sisters, all of whom are supportive of her. Lisa receives minimal services from the regional center because of the family's income, but has been identified as mildly mentally retarded.

Daily Schedule

Lisa's typical workday begins around 7:00 a.m. when she gets out of bed, dresses for work and eats breakfast, prepared by her mother. She gets a ride to work from her sister, arriving to her job by 8:30 a.m. Lisa leaves work at 12:30 p.m., taking public transportation home. She eats lunch which she prepares and takes a nap because of fatigue following work. Lisa enjoys spending the remainder of the afternoon watching television or assisting with housework. Lisa eats dinner, prepared by her parents, around 6:00 p.m. Three or four nights per week, Lisa attends aerobics classes at a fitness center close to her home. She is taken to the class and picked up by her parents. On weeknights, Lisa goes to bed around 10:30 p.m. During weekends, Lisa enjoys

shopping for clothes, running errands for neighbors and performs additional house chores.

Work History, Current Status, and Observation

Lisa graduated from high school and remembered that she was in special classes for reading and math. She described high school as a "terrible experience" because of treatment from peers. Lisa feels that people had a hard time with people who are different and recalls being teased constantly. Following high school, Lisa entered a work training program in a sheltered workshop. Lisa learned to use a time clock, received mobility training to learn public transportation use, and "had a good time, sometimes." She liked the staff at the workshop but did not like to "be around clients that yelled and hit." She also did not like working in large groups where everybody did the same task. Lisa graduated into the supported work program where she was placed in a job enclave at the medical center with three peers. Through the supported work program, Lisa learned the job for which she is now being paid. Gradually Lisa received 1:1 training with a job coach to learn filing and telephone answering to become a receptionist. Lisa stayed in the enclave for three years before being offered an opportunity at competitive employment. Lisa filled out the

job application and was interviewed to be a part-time employee in the personnel department.

Lisa currently works four hours per day answering telephones, filing and collating packets for job applicants. She receives two visits per month from her job coach. Lisa feels she receives adequate support from her work supervisor and that the job coach is no longer needed.

Lisa describes her best skill as filing, feeling completely independent with that task. She commented that more help is needed to assemble personnel packets, but that her supervisor answers all of her questions and "gets her going." Lisa said she does not read well and is still getting used to the forms by sight.

Lisa was observed to have difficulty with memory while working. When answering telephones, Lisa would forget the name of the department. This was fairly usual according to her supervisor, but was improving with fewer observed memory lapses. Lisa was observed to be somewhat shy with unfamiliar co-workers, but was forthright with familiar people and her supervisor. Lisa easily and appropriately reported problems with the job to her supervisor. She remained on task and occasionally did two jobs at the same time, successfully. Lisa was observed to be filing and answering the phones when there was insufficient staff to cover the two jobs. Lisa also requested additional work

when she had completed her assigned work. Her supervisor assisted Lisa to assemble personnel packets by putting the forms in sequential order.

Lisa feels strongly that she has changed since she began the job. She has started to dress up for work and dresses up more often outside work. Lisa recalls only wearing jeans, a sweatshirt and no makeup while in the enclave. She now has her hair styled, wears makeup and dressy clothes. Lisa feels this change in style helps her to assimilate with her co-workers. People in the department are dressed much like Lisa and Lisa did not "look developmentally disabled."

Social, ADL History, Current Status, and Observation

Lisa does not socialize with co-workers outside of work, but does enjoy department celebrations at holiday time and for employee birthdays. Lisa assists with decorations, takes food for potluck lunches and dresses appropriately for the occasion. Lisa seems to be a leader in her office in decorating, having been appointed chairperson of the committee for decorations at the annual holiday party.

Lisa says she has had difficulty finding friends outside of work and as a result rarely socializes outside her family circle. She does visit with neighbors, but does not consider them to be "real" friends she can go shopping

with. Lisa recently met a man at the local bowling alley who was her "boyfriend for a while." She had gone bowling with her sister and her sister's boyfriend when she met the man. Lisa is reconsidering trying the same thing again to meet other people. Lisa does not attend dances, go to nightclubs or belong to interest groups where friends could be found. Lisa has been unable to form friendships with people in her aerobics classes and says, "I guess everybody is too tired to make friends after working out."

Lisa takes family vacations each summer, generally going camping. She shops each weekend, sometimes going with her mother or sisters.

Observing Lisa in a social setting was difficult, but Lisa was observed at a co-workers birthday party. She readily volunteered to cut the cake and serve punch. Lisa listened to other people talking, but rarely spoke herself. She smiled and laughed and seemed interested. Lisa was shy when spoken to but was appropriate and sincere while greeting people. She did not enter into any extended conversations, even with familiar people, during the entire party. She appeared to enjoy herself and took pleasure in being around other people.

At a family gathering, Lisa joked occasionally with her parents and sisters, offering opinions and playing a major

part in family conversations. Lisa was visibly relaxed with her family.

Lisa was immaculately groomed during interviews and observations. She was independent for all basic self-care, taking great trouble with her hair and makeup. She enjoys dressing fashionably, selecting her own clothing. Lisa was taught to use makeup by the saleswoman at the makeup counter at the department store and learned to select clothing by remembering "what the ladies at work wore."

Lisa has had her own checking account for two years. She balances her checkbook monthly and requires assistance to correctly complete the task. Lisa has credit cards that she uses to make clothing purchases. She is pleased to be making regular credit card payments with her income and reported that the balances are low on both cards. She budgets her salary monthly and says the two most important line items are for clothes and public transportation. Lisa does not pay rent to her parents.

Lisa "loves" to take the bus and would like to use public transportation more often. She has gotten lost upon occasion, but knows to call the bus company or 911 if she gets into trouble. She would like to learn how to drive and thought signing up for a driver's education class might be the way to learn. Lisa was unable to describe how she would

go about signing up for a class or finding the class location.

Lisa has no plans to move out of her parents' home. She gets along well with her family and enjoys living with them. She believes that she would have enough money from her job to get an apartment, but realizes she would not be able to buy as many clothes.

Significant Other Interview

Lisa chose her mother as the significant other person to participate in the study. Lisa's mother, Mrs. S, reported that she believes Lisa has undergone developmental changes and she attributed additional change to acquisition of competitive work. After graduating from high school, Mrs. S feels Lisa became happier on a personal level, but that she had difficulty dealing with peers that were more cognitively disabled at the sheltered workshop. Lisa was not interested in participating in adaptive leisure programs and began to show decreased memory and became less verbal. Mrs. S reported that Lisa's personal-care skills remained unchanged and she did not socialize with peers outside of the workshop. Mrs. S thought the workshop offered Lisa a rest from being teased as she was in high school by "normal peers." Mrs. S remembers Lisa as being "ecstatic" when she began working in the enclave at the medical center. Mrs. S

feels that Lisa started to believe that people cared about her, and to gain confidence that she could work around "normal" people. Lisa became more motivated to get up in the morning, but continued to complain of fatigue after work. Lisa talked about the social events at work and felt she was being treated fairly. When Lisa was offered a job, Mrs. S recalled that she wanted to dress up for work and asked to apply for credit cards.

Aside from the concrete changes of dressing and learning to use new income, Mrs. S reported that Lisa began to take more responsibility for her actions and began "using her head," (redefined as common sense) in problem situations, such as using problem solving skills when lost on public transportation. Her family began to trust her more as she went unescorted on shopping trips and home from work.

Mrs. S reported that Lisa needs help balancing her checkbook when the "figures aren't exactly right." Detecting and solving mathematical errors is difficult for Lisa and Mrs. S feels she will need supportive services to manage her money for some time. Mrs. S also believes Lisa needs assistance to self-advocate and learn not to let people take advantage of her. However, Lisa is speaking up for herself more often and Mrs. S has noticed that she talks more about her relationship with her work supervisor. Mrs.

S noted that Lisa has overcome shyness about asking salespeople about the prices of items and will approach appropriate, unfamiliar people for information and assistance.

Mrs. S observed that Lisa has not talked about moving out on her own, but acknowledged that independent living is an option for Lisa. To accomplish this, she feels Lisa would need to learn how to prepare meals, shop for groceries, and have effective compensatory techniques for daily money management.

Summary

Lisa lives with her family and is employed as an office assistant. She is taken to work by her sister, but uses public transportation to return home from work and for leisure outings. Lisa is a high school graduate. She was employed by a sheltered workshop and supported work program before being competitively employed.

Lisa no longer receives direct job assistance from her job coach, relying mostly on her supervisor and co-workers for support. She was dressed appropriately with styled hair, makeup, and dressy clothes which Lisa reported helps her "blend in" with co-workers. Lisa assists with office parties and when she completes her work, asks for additional

tasks. She occasionally experienced difficulty with memory while answering phones.

Lisa socializes with her family and, infrequently, with her sister's friends. She was also observed not to have difficulty socializing in her family circle, but was shy during office social occasions. Lisa reported that she has no real friends, nor does she socialize with co-workers outside work. She has several hobbies including attending aerobic classes, watching television and shopping.

Lisa is independent for self-care and manages money and her credit cards with her family's assistance. She has no plans to move into her own apartment but thinks about this option. Lisa requires assistance for meal preparation and other advanced level ADL.

Mrs. S, Lisa's mother, reported that Lisa has begun to show more confidence, dress in a more age appropriate way and show more motivation in her life since becoming competitively employed. She noted that Lisa is demonstrating the use of "common sense" and that the family trusts that she will respond correctly should Lisa experience an emergency in the community.

Socializing has always been difficult for Lisa, Mrs. S reported, although she has more social skills now than when she entered competitive employment.

Results

The first question answered by this study was: what are the differences perceived by persons who have mental retardation in their ability to be successful in non-work activities before and after engaging in competitive employment? All of the subjects recognized increased earnings as a direct result of working. Lisa identified that she could pay off her credit cards and buy more clothes. Larry bought a new truck and Mike purchased a used truck with earnings. Roger understood that he made more money, but saw no benefit because his earnings went to the board and care operator and his allowance has not changed. He appeared to understand that this extra money would give him more leisure options as he was willing to seek help from the regional center to have his money provided to him directly. Lea acknowledged that she received more money as a result of her job, but was unable to describe if this affected her, except to say she went to movies or out to eat pizza.

The subjects pursued different leisure activities than they had previously which were directly related to increased earning power. Two subjects belonged to fitness gyms for which they paid from their earnings. Larry bought more oil painting supplies to augment his oil painting hobby and more meals in restaurants with his earnings.

The second question this study answered was: which work behaviors learned at competitive jobs do individual adults with mental retardation and their significant others report as having an effect on their non-work lives?

Several behaviors that were enhanced or learned while competitively working were identified by subjects and their significant others or observed by the researcher, to be used in non-work domains. Self-advocacy, or the ability to express needs and seek help from other people, was commonly identified by subjects' significant other people to have become visible in non-work areas, especially while shopping. Increased effectiveness in social situations, with less fighting and increased impulse control were identified as skills learned at work that were used at home. Subjects' significant others reported more appropriate dressing, increased confidence and, in one case, cleaning agents used at work were purchased by the subject for home use. Also identified was a learning style used at work that was proving effective as a method to learn money management.

CHAPTER 5

DISCUSSION, SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

This chapter presents discussion of the results, reviews the first four chapters, presents conclusions, and makes recommendations for future research.

Discussion of the Results

A discussion of the results will be presented in this section. Common trends will be identified in the areas of work, self-care/ADL and leisure/social functioning.

Work

All five subjects were employed in one of the three following areas: landscape maintenance, office work, and janitorial services. One subject, Roger, worked in outside maintenance and indoor janitorial tasks as part of the same job. Three subjects performed their daily jobs with no weekly intervention from a job coach while two subjects required weekly intervention in the form of actual job instruction or job coach assistance to complete the job. Two subjects required significant support from supervisors and job coaches to stay on task and get the job completed. These two individuals, Lea and Roger, required verbal cues with physical presence of supervisors to return to a task

once interrupted, or for pacing themselves by maintaining a constant work activity level. Lea consistently stopped after a short time of working, complained of fatigue, while Roger was easily distracted from a task by interruptions from co-workers. The remaining three subjects, Mike, Larry and Lisa, were able to remain on task independently and return themselves to work following interruptions.

All five subjects were considered to have adequate safety awareness in the performance of their jobs, with the exception of Lea. Her fatigue level may have significantly lowered her safety awareness; however, this was not observed. High level safety awareness was a factor for each subject since they handled machinery, toxic cleaning chemicals and were in high traffic situations (for example Roger cleaned the parking area of a busy fast food restaurant).

Subjects used a variety of techniques and had differing styles in their relationships to supervisors and co-workers. Larry rarely saw his supervisor and used functional, social greetings with the supervisor, cooks and bookkeepers as they came to work. He actually performed his job out of the presence of others. He was alone most of the time at work. However, Larry felt comfortable in approaching his supervisor with job-related problems. Mike had daily dialogue with his supervisor, although mostly performed his

job away from the supervisor and co-workers. Mike was able to talk with co-workers on a daily basis if he desired during lunch and at the start and finish of each day. Ideally, Lea would have performed her job as a solo worker, but required so much verbal assistance to keep working, that she saw her supervisor each hour and occasionally fractions thereof. Lisa had the most normalized "relationship" with her supervisor and co-workers. She was able to approach her supervisor with job-related problems, but also engaged in "office talk" that co-workers initiated. When conversation turned more personal in nature, at office celebrations, Lisa became shy and not as verbal. However, she did remain part of the group at that time by actively participating, for example, cutting cake and helping to decorate. Roger actively participated in most conversations, stopped work while attempting to engage in conversations having nothing to do with himself. Roger was unable to assimilate with co-workers as he spoke loudly in an interfering way, speaking more loudly if he felt unheard. He was also unable to speak appropriately on the topic being discussed. All five subjects viewed their supervisors positively. Subjects viewed supervisors as teachers with whom they could discuss their job-related problems.

Four subjects had never had contact with co-workers outside the work setting, with the exception of Mike. He

had gone with a co-worker to the fitness gym after work. He was unable to express why he had not kept up the outside work relationship with this person.

All subjects attended high school, participating in special classes, except Roger who had never attended high school. Lisa and Mike were very vocal about the negative treatment they had received from peers while in high school. Each subject began their work experience in sheltered workshops. All expressed specific problems in the sheltered setting, most notably: peers who were functioning at a lower level than themselves, boredom with the program, and too much noise or fighting.

Three subjects went from sheltered employment to the supported work enclave and on to competitive employment. Two subjects went directly from supported employment to the competitive work setting. All began competitive employment with the assistance of job coaches, requiring daily intervention.

Questions regarding changes that occurred as the result of competitive employment brought varied responses. Each subject had difficulty with his abstract question and needed clarification with examples before answering.

Lisa identified a change in her appearance since beginning her job. She wears dressy clothes and makeup to work and wore jeans and a sweatshirt to work while in the

enclave. Lea's significant other feels that she is wearing appropriate clothing more often, and arriving to work and non-work related appointments on time with increasing frequency since working. Lisa's mother reported that she is taking more responsibility for her life and is showing more common sense to solve problems. Roger's board and care operator believes that Roger is less likely to fight now than before being competitively employed, and is showing more patience while dealing with his roommates. She also reported that Roger is not busy enough as a competitively employed person only working part time. Larry identified that he uses some of the same cleaning agents at work and home and that he learned cleaning methods at work that he uses at home.

When questioned about how they feel about themselves since getting competitive jobs, subjects who were able to answer felt positive about their accomplishments. Roger felt that he was doing "real work" and "man's work," indicating that he did not feel that way prior to getting the job. Lisa felt that people cared about her and she had proven she could work among "normal" people. Mike was proud of his ability to progress through several steps in work tasks and is accepting more job responsibility as he learns.

Subjects who reside at home with their families, or lived independently with close family support were

performing more satisfactorily than those subjects with little or no family support. Subjects with close family support were more independent with self-care and while working. They required fewer interventions from job coaches and supervisors than those without family support.

Self-Care/ADL

All subjects were independent for basic self-care such as dressing, grooming, and bathing. Two subjects appeared to have only marginal competence in maintaining a neat appearance for work. Roger had few resources to get well-fitting clothes that are in good repair. He also was impulsive in self-care tasks and often did not complete the task thoroughly. Lea appeared fatigued, oftentimes had dirty hair and clothing. This situation has improved with Lea requiring fewer reminders to go home from work to change her clothes. Larry asked that the researcher not observe him completing basic self-care. However, he always appeared meticulously groomed and stylishly dressed.

Three of the subjects did not "appear" to have developmental disabilities. They could not be picked out from a crowd as looking different. Roger appeared "different" because of his impulsive, exaggerated movements, disorganized dressing and way of speaking. Lea seemed

different because of her slow movements and overall appearance.

Larry and Lea lived independently of family or other supported living arrangements. Lea received assistance from a life skills counselor weekly. The counselor assisted with money management, shopping, meal preparation and housekeeping. Larry required assistance with money management but was able to manage his home independently. Lea's deficits in the self-care domain closely paralleled her work deficits. She needed constant cuing to complete the work and initiate the next task in sequential order. Both domains appear equally impaired. Larry's lack of money management skills appear to be a cognitive deficit that affects only money management. He reads, writes and can compensate for most deficits.

Mike and Lisa live with supportive families. Both perform specific ADL within their homes. Both assist, rather than lead, in accomplishing household tasks. They were able to initiate the task once it was assigned. For example, Mike was able to clean common areas in his house, while Lisa was able to assist with some housework.

Roger lives in essentially a board and care environment with little support. He is a leader among his peer group where he directs house cleaning. Roger attempts to lead at work, but this does not work because his co-workers are not

developmentally disabled as are his roommates. Roger is able to initiate basic self-care as he initiates tasks at work.

All five subjects followed daily schedules with little variance. Each subject worked the same hours daily, going to and from work the same way with set activities following work. Subjects worked three or four hours per day and watched television after dinner until bedtime. The similarities in daily schedules paralleled how they work. Subjects generally followed a set routine to do their jobs, uniformly completing the tasks without variance, following a prescribed set of steps.

All five subjects were independent to wash and dry their laundry, and two subjects iron their own clothes. Larry and Lea work independently, although Lea is currently being trained to shop for food and prepare balanced meals.

Leisure/Social

The subjects pursued different leisure activities which were directly related to increased earning power. Two subjects belonged to fitness gyms for which they paid from their earnings. Larry bought more oil painting supplies to augment his oil painting hobby and more meals in restaurants with his earnings.

Larry, Lisa and Mike engaged in solitary activities during their leisure time. Watching television, oil painting, shopping and window shopping were leisure activities that these three subjects enjoyed by themselves.

All subjects reported that they did not see co-workers during non-work hours and only Lisa currently has extended social relationships at work. She socialized with other workers at lunch, during breaks and during office celebrations. Mike socialized with workers who were formerly in his supported work enclave at lunch and during breaks. He does not socialize with "normal" peers generally, except for social greetings. Mike went to the gym with a co-worker a few times, but has not recently (in the past year) seen anyone socially from work.

Subjects reported being involved with adaptive leisure groups at different times in their lives. Roger continues to be actively involved with special leisure programs. The remaining four subjects reported that they have nothing in common with people as they see them as being "more retarded" than themselves. Yet, they have few social outlets since their social skills to make friends with non-retarded peers are inadequate. This problem has been observed since people with developmental disabilities began moving into competitive employment. As people with developmental disabilities begin to move away from the retardation system

for work, friends are left behind and the competitive worker may be left without a social support system that is not family oriented.

The two subjects with the strongest social network outside the family unit were the people who had little or no support from their families. Roger has an active social life, including his friendship with the police officer. He attends adaptive leisure activities and has daily contacts with people whom he considers friends. While he has a competitive job, he has maintained relationships with peers who have developmental disabilities. He lives in the mental retardation system, and has access to the social benefits.

Lea lives independently, but receives concrete services from the mental retardation system in the form of a life skills counselor. She lives with people whom she considers to be friends. Although Lea's significant other person, when interviewed, thought her social network was marginal, Lea was satisfied with her boyfriend and friends. She was willing to advocate for her friends and demonstrated an understanding of social dynamics between herself and family with regard to her boyfriend who is African American. Lea was the only subject who had an ongoing intimate relationship. Lea's life changed when she began living independently, which coincided with her getting a job and meeting her boyfriend.

Each subject lacked social skills to begin relationships with people who do not have developmental disabilities. Subjects could not identify community resources that might be used to achieve social skills training.

Summary

The first purpose of this study was to explore if there were observable and self-perceived associations between the acquisition of competitive employment and quality of life for adults who are mentally retarded.

The second purpose of this study was to attempt to describe skills and work behaviors of subjects' skills, to include any capability a subject must have to complete a specific competitive job, and the ability to maintain and increase competitive skills. Work behaviors included time management on the job, the ability to establish and maintain interpersonal working relationships with co-workers and supervisors, and the ability to initiate and stay on task. The study was guided by the occupational performance frame of reference. A person's successful functioning in self-care, work and leisure depends on skill level and the ability to compensate in sensory, motor, psychological social and cognitive components. Occupational therapists

serve to facilitate learning, teach compensatory techniques and assist with skill acquisition in life roles.

There was limited evidence of research that addresses the effects of competitive employment in the non-work life of adults with mental retardation. Through documentation of positive and negative effects of competitive employment on leisure and self-care roles, a foundation has been established for occupational therapists and other service providers which may change or enhance training modalities.

A review of the literature yielded no information on the effects of competitive employment on the leisure and self-care roles in the lives of developmentally disabled adults. However, the literature did suggest that work provides structure in a person's life around which supporting skills are required to insure success at one's job (Diasio, 1978; Halpern, Close & Nelson, 1986; Kiernan & Stark, 1986). Further, work was viewed as a focal point in many adults' lives, and that the positive feelings generated by successful work may be generalized into a person's non-work life (Kielhofner, 1980). Failure to achieve basic functioning in self-maintenance, productivity, and leisure may lead to the acquisition of an unhealthy lifestyle (Reed & Sanderson, 1983).

A case study design was used to yield data about the acquisition of competitive employment and changes that may or may not have occurred in subjects' lives as a result.

Five adult subjects with diagnosed mental retardation, who had worked competitively for at least three months, participated in the study. Each subject was interviewed and observed as they completed ADL, participated in leisure or social activities, and while working at their jobs. Each subject selected a significant other person who knew the subject before and after gaining competitive employment. Significant others were interviewed regarding pre and post competitive work lifestyles of subjects.

Conclusions

In conclusion, results of this study showed that there are observable and self-perceived associations between the acquisition of competitive employment and quality of life for the five subjects involved in the research.

Each subject realized increased earning power and most subjects spent more money in their daily lives. Subjects did spend their earnings to increase competency in non-work roles as the literature suggested. Each subject, with the exception of one, spent earnings to increase competency in leisure and self-care roles.

Obtaining competitive employment for three subjects removed them from the developmental disability service network. This distance decreased their opportunities for social involvement since subjects lacked skills to make social contact with "normal" peers outside of work. When people with developmental disabilities become competitively employed, work skills are satisfactory but lack of social skills can leave a void in their lives. Subjects who had strong family support may feel the void when parents die and siblings do not have time to continue with daily social support. Four subjects considered to have mild level mental retardation had more difficulty socially, lacking skills to associate with non-retarded peers, but feeling too "high level" to comfortably engage with others who were labeled developmentally disabled.

Subjects expressed feelings of increased self-esteem, ability to self-advocate at work and overall increased skill level in community mobility because of competitive employment. Three subjects felt they were more a part of the general society because of competitive employment and benefits derived from their jobs.

Recommendations

As a result of this study, it is recommended that occupational therapists and others develop and

advocate for programs which integrate competitive employment training and social skills training. Adults with developmental disabilities need comprehensive programs that train across work, self-care and leisure roles. Programming that is not holistic can continue to promote competency in one role while leaving a person incompetent in other life roles. Adults with developmental disabilities require concrete, step training programs to gain competency in social and self-care roles, similar to the training provided in competitive work training models.

Occupational therapists as professionals are in a unique position to develop and provide comprehensive programs as adults with developmental disabilities strive to achieve normal roles. Occupational therapists can assist individuals with developmental disabilities to increase performance in sensory, motor, psychological, social and cognitive functioning so that they may achieve competence in work, self-care and leisure.

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APPENDIX A
SUBJECT'S INFORMED CONSENT



A campus of The California State University

School of Applied Arts and Sciences • Department of Occupational Therapy
One Washington Square • San José, California 95192-0059 • Main Office: 408/924-3070 • Fieldwork Office: 408/924-3078

AGREEMENT TO PARTICIPATE IN RESEARCH AT SAN JOSE STATE UNIVERSITY

RESPONSIBLE INVESTIGATOR: Jill Chesley

TITLE OF PROTOCOL: The Effects of Normalized Occupation on the Lives of People with Developmental Disabilities.

I have been asked to participate in a research study that is looking at the effects of a "real job" on people with developmental disabilities. The results of this study should further our understanding of what happens to people's lives when they get a "real job."

I understand that:

- 1) I will be asked to participate in interviews, allow the researcher to watch me at work, home, and during my free time.
- 2) the possible risks of this study are that I may feel uncomfortable when I am watched at work, home, or during free time.
- 3) the possible benefits of this study to me are that I will be able to tell the researcher how I feel about things I learned at work.
- 4) no alternative procedures will be used.
- 5) the results from this study may be published, but any information from this study that can be identified with me will remain confidential and will be disclosed only with my permission or as required by law.
- 6) no compensation will be given.
- 7) any questions about my participation in this study will be answered by Jill Chesley (916) 893-2464. Complaints about the procedures may be presented to Lela Llorens, Ph.D., advisor for Jill Chesley; Department Chair for Occupational Therapy at (408) 924-3072. For questions or complaints about research subject's rights, or in the event of research-related injury, contact Serena Stanford, Ph.D. (Associate Academic Vice President for Graduate Studies) at (408) 924-2480.
- 8) my consent is given voluntarily without being forced; I may refuse to participate in this study or in any part of this study, and I may stop at any time, without prejudice to my relations with SJSU.
- 9) I have received a copy of this consent form for my file.

I HAVE MADE A DECISION WHETHER OR NOT TO PARTICIPATE. MY SIGNATURE INDICATES THAT I HAVE READ THE INFORMATION PROVIDED ABOVE AND THAT I HAVE DECIDED TO PARTICIPATE.

DATE

INTERVIEWEE'S SIGNATURE

INVESTIGATOR'S SIGNATURE

APPENDIX B
INTERVIEW FORM FOR SUBJECTS

SAMPLE INTERVIEW FORM
(for subjects)

Name of subject: _____

Date of interview: _____

Place of interview: _____

1. Describe your day beginning with waking up in the morning?
2. How does work make you feel?
3. Describe an example of something you learned at work that you use at home.
4. If you have a question at work, who do you ask?
5. What tasks can you do well?
6. If you have a problem, who do you talk to about your problem?
7. What do you do for fun?
8. Have you made any new friends in the last six months?
9. Describe a non-work activity you do with people you know from work.
10. How have things in your life changed since you started to work?

APPENDIX C
OBSERVATION FORM

SAMPLE OBSERVATION FORM

Name of subject observed: _____

Date of observation: _____

Place of observation: _____

Activity observed: _____

1. Observe in work setting: attention to task, use of breaktime, ability to work as a team member and independently, ability to initiate and motivation to complete job.
2. Observe activities of daily living: (basic self-care; grooming, dressing, etc., high level activities of daily living; meal preparation, laundry, and community mobility) ability to complete task following correct sequences, ability to complete activities of daily living in a timely way.
3. Observe leisure time: (Leisure activities specific to individual subjects) Activities enjoyed, skills employed during leisure time pursuits, social skills used, note people interacting with (relative, friend, etc.), participation in organized activity.

APPENDIX D
SIGNIFICANT OTHERS INFORMED CONSENT



A campus of The California State University

School of Applied Arts and Sciences • Department of Occupational Therapy
One Washington Square • San Jose, California 95192-0059 • Main Office: 408/924-3070 • Fieldwork Office: 408/924-3078

AGREEMENT TO PARTICIPATE IN RESEARCH AT SAN JOSE STATE UNIVERSITY

RESPONSIBLE INVESTIGATOR: Jill Chesley

TITLE OF PROTOCOL: The Effects of Normalized Occupation on the Lives of People with Developmental Disabilities.

I have been asked to participate in a research study that is an investigation of the effects of normalized work on the lives of adults with developmental disabilities. The results of this study should further our understanding of work behaviors which affect non-work components of a mentally retarded adult's life.

I understand that:

- 1) I will be asked to participate in an interview lasting one to one and one-half hours.
- 2) there are no risks associated with this interview.
- 3) the possible benefits of this study to me are learning what [subject's name] has gained or not gained by being competitively employed.
- 4) no alternative procedures will be used.
- 5) the results from this study may be published, but any information from this study that can be identified with me will remain confidential and will be disclosed only with my permission or as required by law.
- 6) no compensation will be given.
- 7) any questions about my participation in this study will be answered by Jill Chesley (916) 893-2464. Complaints about the procedures may be presented to Lela Llorens, Ph.D., advisor for Jill Chesley; Department Chair for Occupational Therapy. For questions or complaints about research subject's rights, or in the event of research-related injury, contact Serena Stanford, Ph.D. (Associate Academic Vice President for Graduate Studies) at (408) 924-2480.
- 8) my consent is given voluntarily without being forced; I may refuse to participate in this study or in any part of this study, and I may stop at any time, without prejudice to my relations with SJSU.
- 9) I have received a copy of this consent form for my file.

I HAVE MADE A DECISION WHETHER OR NOT TO PARTICIPATE. MY SIGNATURE INDICATES THAT I HAVE READ THE INFORMATION PROVIDED ABOVE AND THAT I HAVE DECIDED TO PARTICIPATE.

DATE

INTERVIEWEE'S SIGNATURE

INVESTIGATOR'S SIGNATURE

APPENDIX E
SIGNIFICANT OTHERS INTERVIEW

SAMPLE INTERVIEW FORM
(For care provider, relative, friend)

Name of subject: _____

Name of interviewee: _____

Relationship of interviewee to subject: _____

Length of time subject known to interviewee: _____

- 1A. What types of self-care and household related tasks did _____ perform prior to beginning competitive employment?
- B. What was _____ level of motivation regarding the initiation and completion of these tasks prior to beginning competitive employment?
- 2A. How did _____ view him/herself prior to beginning competitive employment?
- B. How does _____ view him/herself since beginning competitive employment?
- 3A. How did _____ relate to other people at home (or during leisure hours) 12 months ago?
- B. How does _____ relate to other people at home (or during leisure hours) now?
4. What does _____ talk about at home or during leisure time?
5. Has _____ taken on any new hobbies in the last _____ months?
- 6A. How did _____ make his/her needs and feelings known _____ months ago?
- B. How does _____ make his/her needs and feelings known now?